February 28, 2023
RE: HB 2927 STATEWIDE STEERING COMMITTEE ON SICKLE CELL DISEASE

Dear House Committee on Behavioral Health and Care,

I am a registered nurse at a hospital in Portland and I care for patients living with Sickle Cell Disease in the pediatric inpatient hospital setting. I am testifying in support of HB2927.

Sickle Cell Disease is a complex inherited blood disorder that requires life-long coordinated care from numerous aspects of the community and healthcare system. As a pediatric hematology/oncology nurse, I encounter this population of patients who come into the hospital experiencing both acute and/or critical health complications due to this chronic disease.

When a patient with Sickle Cell Disease comes into the hospital, they need a very specific course of treatment depending on the presenting complication. A patient in severe pain from a vaso-occlusive crisis (an obstruction in the blood vessels caused by irregular C-shaped red blood cells that compromises blood flow and oxygenation to vital organs), requires rapid treatment of pain and mitigating triggers to prevent life-threatening complications. It is vital that these patients encounter health care providers knowledgeable in recognizing and managing these conditions. One study from 2021, reported that only 53% of patients with Sickle Cell Disease are either “always” or “usually” satisfied with their ED care. 50% of the sample from this study reported a delay of at least 2 hours for care[1]. Several other research studies over the past decade report poor quality pain management and disparities in the care of this patient population. I encourage you to watch and listen to this video of patient stories who live with this chronic disease: https://www.youtube.com/watch?v=yCOvkOCaaSk&t=231s. I have no affiliation with the medical center associated with this video.

Individuals impacted by Sickle Cell Disease in our community need to have an established system of support where there is space to acknowledge their personal struggles and provide equitable services and education to meet their complex and dynamic physical, social, and emotional care needs. I want to emphasize how important it is to have a Statewide Steering Committee that is devoted to understanding how to best serve this marginalized population and provide them access to coordinated care across the community.

I strongly advocate for voting in favor of this important bill.

Thank you,

Samantha Porter, MN, RN
Certified Pediatric Hematology/Oncology Nurse
Certified Pediatric Nurse
Portland, OR

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[1] Crego, N. , Masese, R. , Bonnabeau, E. , Douglas, C. , Rains, G. , Shah, N. & Tanabe, P. (2021). Patient Perspectives of Sickle Cell Management in the Emergency Department. *Critical Care Nursing Quarterly, 44* (2), 160-174. doi: 10.1097/CNQ.0000000000000350.